LQA Summary Data: Trends, Issues and Needs
FY 2002/03

Introduction

Since 1997, the Area VI Board has conducted Life Quality Assessments (LQA's) for individuals who use regional center services living in the area of Amador, Calaveras, San Joaquin, Stanislaus, and Tuolumne counties.   On January 1, 2003, the Area VI Board joined organizationally with the State Council on Developmental Disabilities. This new partnership provides increased effectiveness in statewide coordination of systems advocacy and resource development. The LQA projects continued under the new organizational umbrella.

The assessments, or LQA's, are intended to capture the individual's perspective on the quality of his or her life, in order to enrich the individual's planning process.   Summaries are routinely conducted for persons who live in situations other than with their family of origin. However, any regional center client can request and receive an LQA visit.   In addition to the individual planning process, the LQA summaries provide an overall view of the issues, concerns, and needs experienced by eligible adults and children with developmental disabilities. As part of the State Council on Developmental Disabilities' mandate to identify issues and needs for persons with developmental disabilities, the LQA Summary data results have also been reviewed in aggregate.

Just as the individual summaries are intended to contribute to but not supplant an overall planning process, so this report is intended to be one tool in the information gathering and assessment process that underlies effective resource development.   LQA data is highly subjective, reflecting as much as possible the individual's self perceptions at the time of the visit.   The more successful the visitor is in catching that perception, the more useful the LQA is in informing the individual's planning team of personal needs and concerns. Trends in aggregate data represent common experiences, and as such, provide vital insights into the service system and generic support systems in our communities.

Project Design

The format, methods, and standards for conducting LQA visits were developed by DDS and are standardized throughout the State of California.   This project relies primarily on trained volunteers, who receive a stipend for completing summaries, expected to generate over 12,000 volunteer hours over the duration of this three year project cycle. The project is staffed by two CPS position and a half-time Office Assistant.
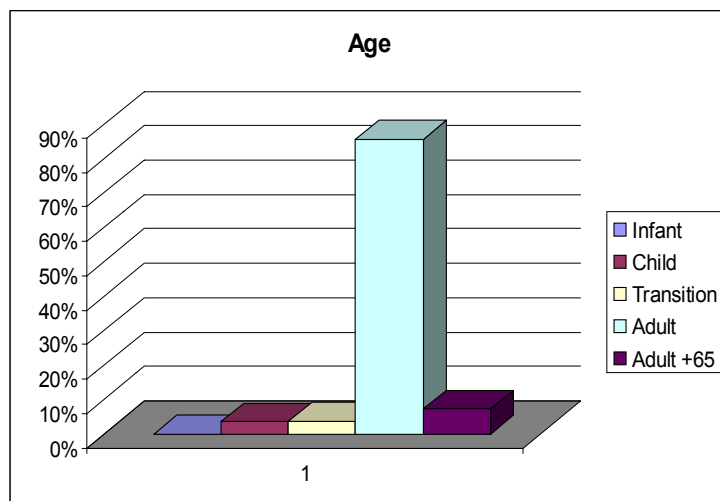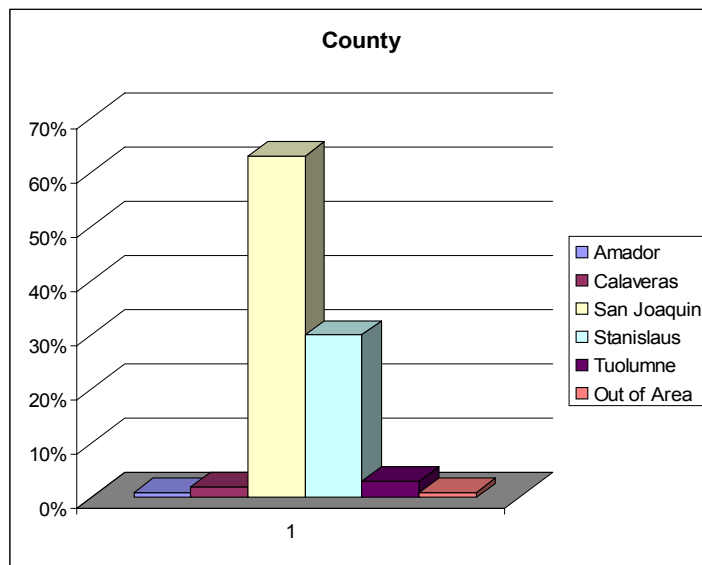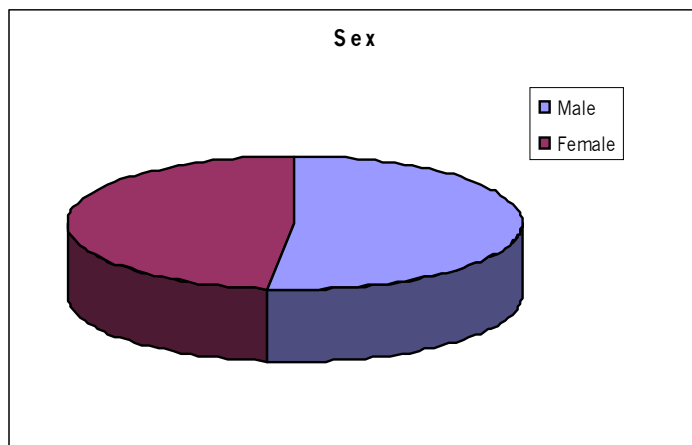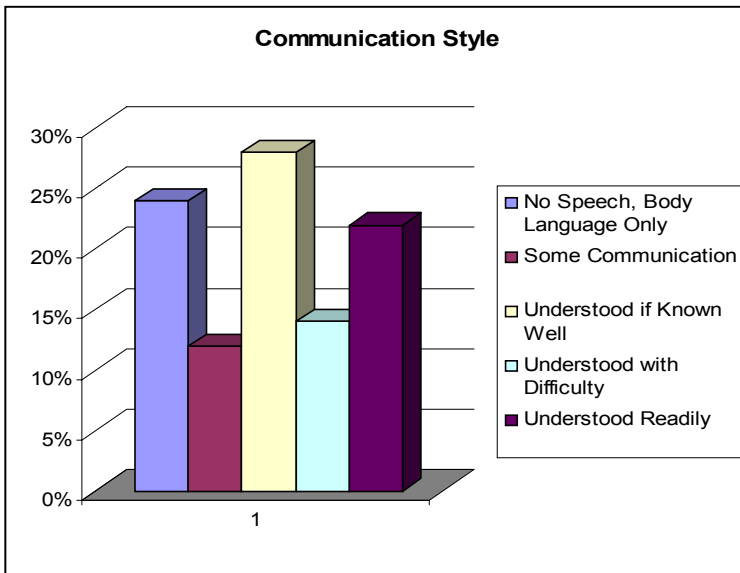
LQA Summary Results

The LQA process looks at 25 life outcomes, grouped into six areas.   For each outcome, the visitor indicates either "OK at this time" or "Needs Follow-up", and then documents the observations and comments that explain their conclusions. "Needs Follow-up" is indicated for several reasons. The visitor may not have been able to observe any information about that particular outcome, so the status is unknown.   "Needs Follow-up" can also reflect known issues that are being addressed but not fully resolved, or issues that most probably can't be changed but rather reconciled, such as physical losses related to aging.

Overview

The second year of this project cycle produced very similar results to the first year. Visitors and LQA staff completed 550 visits, and attempted to complete an additional 273 visits. These attempted visits were not completed for a variety of reasons, such a major illness or incarceration. People also declined to have visits. Some people declined because they felt their lives were going very well. Others declined for a variety of personal reasons, such health and family demands. Visitors and staff were unable to contact 70 individuals. For each of those individuals, Valley Mountain Regional Service Coordinators were helpful in efforts to make contact. By far the majority of Service Providers were also very supportive of each person's right to have a Life Quality visit.

As in past years, visitors found that most of the people they visited are in safe situations and that their basic needs are supported successfully. The living arrangements and supported day time activities varied through a wide range of service options. Visits were conducted in all five counties of the VMRC catchment area, and both adults and children living in situations other than with their family of origin were visited. People who were visited during the second year of the project were contacted for repeat visits this year. Visitors usually found that issues raised in the previous visit had been addressed, particularly those who had had potential rights violations, and saw significant improvements in the quality of day time activities and home life for those individuals.

Sex

County

Age

2

Communication Style

Legend:
- No Speech, Body Language Only
- Some Communication
- Understood if Known Well
- Understood with Difficulty
- Understood Readily

(Y-axis: 0% to 30%)

Daytime Activities

Legend:
- No Program
- VMRC Funded Program
- Work Activity Program
- Supported Employment
- School
- Other

(Y-axis: 0% to 70%)

Type of Residence

Legend:
- CCF
- ICF
- Skilled Nursing
- Foster Home
- Ind/Supported LIving
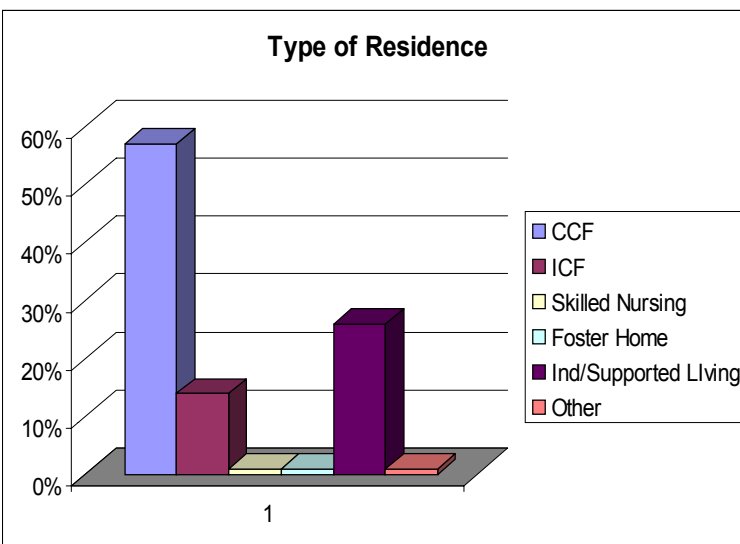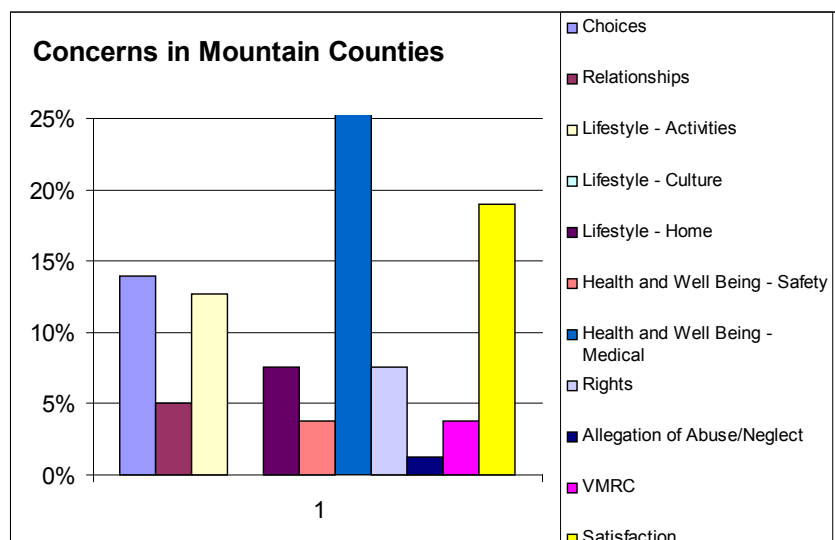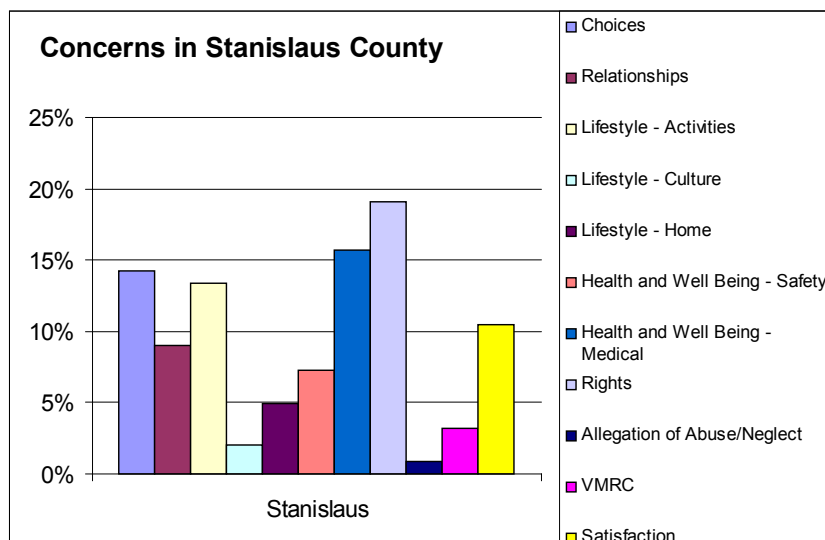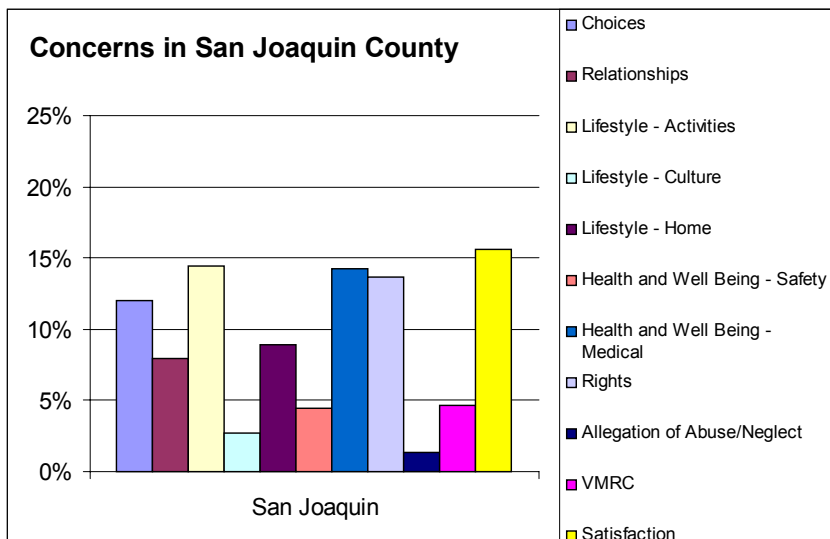- Other

(Y-axis: 0% to 60%)

The majority of people visited lived in a community care facility, ranging from 6 bed up to 49 beds. They attended a regional center funded program. That majority represents not only the most common circumstance for VMRC clients, but are also the people most likely to agree to a visit. People living independently with minimal supports were mostly likely to refuse a visit.

During this project cycle, the only Habilitation funded work activity program in San Joaquin county closed. There is one work program left in the VMRC catchment area, in Stanislaus County. Supported employment continues to serve a small percentage of adults in this area. With the exception of a small attendance at other publicly funded programs such as community colleges, adult day treatment or substance abuse rehabilitation programs, adult daytime activities were primarily funded by the regional center.
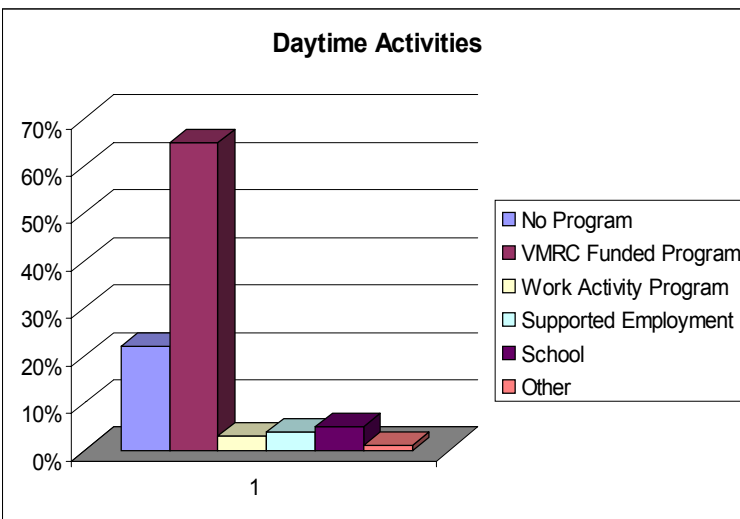
The pattern of issues raised remained remarkably consistent in each of the counties. Some of those patterns are predictable. Access to medical services is a greater concern in the mountain counties. Some trends probably reflect the overall community culture. Again, in the mountain counties, people typically express a greater sense of autonomy and have fewer concerns about rights. Trends across all five counties may suggest systemic issues. In each of the five counties, for example, about 5% of people visited had concerns about VMRC. Concerns were most commonly related to staff turnover, rapidity of staff response, and the desire to get regular individual financial account statements.

Concerns in San Joaquin County

Legend:
- Choices
- Relationships
- Lifestyle - Activities
- Lifestyle - Culture
- Lifestyle - Home
- Health and Well Being - Safety
- Health and Well Being - Medical
- Rights
- Allegation of Abuse/Neglect
- VMRC
- Satisfaction

(San Joaquin)

Concerns in Stanislaus County

Legend:
- Choices
- Relationships
- Lifestyle - Activities
- Lifestyle - Culture
- Lifestyle - Home
- Health and Well Being - Safety
- Health and Well Being - Medical
- Rights
- Allegation of Abuse/Neglect
- VMRC
- Satisfaction

(Stanislaus)

Concerns in Mountain Counties

Legend:
- Choices
- Relationships
- Lifestyle - Activities
- Lifestyle - Culture
- Lifestyle - Home
- Health and Well Being - Safety
- Health and Well Being - Medical
- Rights
- Allegation of Abuse/Neglect
- VMRC
- Satisfaction

(1)

4

Emerging Trends

Forty-one percent of the people visited identified no follow-up needs, and the majority of those who identified follow-up needs had less than three issues. In most instances, service coordinators were aware of individual concerns.   Most issues were also familiar to the project.   But in aggregate, several trends emerged.

Residential Services
This year, visitors observed a decided increase in the number of people unhappy with their living situations. Five per cent of those visited specifically stating that they wanted to change their living situation.   These individuals are in addition to those who expressed specific complaints about their home, such as not liking food or wanting their own rooms. People having their own rooms in care facilities expressed greater satisfaction overall.   The majority of these individuals wanted to live in their own homes, describing support needs typical of those provided by supported living agencies. Complaints about care homes generally related to wanting more choices, housemate relationships, and the lack of community activities.   In the second six months of this cycle, visitors heard more complaints about cutbacks in weekend activities.   Ten individuals specifically reported that their homes had reduced weekend activities because of staff, transportation, and access costs.

Cutbacks were also cited by individuals receiving supported living services.   These were elimination of transportation to medical appointments, cutback of worker support during the medical appointments, elimination of support to attend gyms, reduction in transportation for individuals with small children, and overall reductions in the number of service hours.

Two conservators questioned the limited availability of care facilities serving geriatric individuals. Four people visited in skilled nursing facilities expressed strong dissatisfaction with their situations. The appropriateness of the placement for two of those individuals was questioned by facility staff.

Day Activity Services
One fifth of the people visited expressed dissatisfaction with day program and work services. Twenty-three individuals (4.2%) specifically requested a change in day program, almost all related to the complaint that their day program was "boring" or did not provide enough to do. Seventeen individuals not currently using services stated that they would like more community activities, but had rejected participation in day programs as boring, stigmatizing, or unable to meet their activity preferences. Sixty individuals, 11% of those visited, wanted a job.   An additional seven people identified underemployment concerns, i.e., wanting more work hours or better paid work.   These results become even more pronounced when communication style is considered.   Thirty-six percent of the individuals visited relied primarily on support staff as informants for their summaries. When possible, family members were included in the visit. But paid work was not a concern raised by this group. Adjusting for that factor, 19% of people visited specifically requested work or improved work situations. While program changes in various counties might explain concerns from those involved individuals who also happened to have LQA visits, this is a second year trend, and a significant change from the first three years of the project. Because the LQA assessment

tools have not changed, and because the trend is consistent across visitors and counties, this data certainly deserves further consideration. It is especially compelling given that employment patterns are changing in this area generally, and more of the jobs people have are in groups through regional center funded programs. The area wide pattern also suggests systemic issues. It should also be noted that the LQA interview format does not assess individual barriers to employment.

Medical
The previous year, health emerged as a major area of individual concerns. Although the numbers were lower than last year, the overall trend was the same as in the previous year. Service Coordinators were almost always aware of medical needs, and visitors observed some very carefully organized and managed services for individuals with complex needs. Difficulties were most often systemic or attitudinal barriers. Needs included adaptive equipment or equipment repairs, follow-up with specialist, wellness activities to maximize health such as smoking cessation and weight loss. Sleeping disorders emerged again as a health problem. Access to services not covered by Medi-Cal, including medications, or not provided with sufficient frequency, such as glasses, was also a concern. The practice of individuals having to change their doctors when they move to a new care home was observed again this year. Individuals did not view choice of health providers as something they could do. OB/GYN services, specifically preventive exams and testing, were typically available to women visited. Dental needs were identified by 24 individuals. This year, visitors also began hearing more dissatisfaction with dental clinics, their only service option with Medi-Cal changes.

Mental Health
A small percentage of people visited identified needs in most areas of their lives. These people were characterized by frustration with VMRC support and available services. They also frustrated by income limitations. They were usually identified by Service Coordinators as having "severe reputations", and a history of burning out Service Coordinators with frequent demands. Mental health services also did not provide adequate supports. Often, supported living services were being provided in an attempt to meet identified needs. There did not seem to be a means for identifying and addressing the underlying mental health needs. While the number of these individuals is comparatively small, their intense use of case management resources could warrant development of targeted services.

Families with Dependent Children
Visitors were excited to meet with 24 individuals who had children under the age of 18. When those children were living with them, these families typically received supported living assistance and were satisfied with those services. Five parents requested additional parenting support services, including skills training and day care. Four individuals had legal concerns regarding custody. Fourteen individuals wanted employment that would accommodate their family needs. Four families were living in substandard housing in unsafe neighborhoods. Other needs included social and recreational resources, generic resources including Headstart, and counseling. Three families were struggling with family violence issues. Three families were non-English speakers, and encountered service and community barriers as a result.

Spiritual Needs
Unmet spiritual needs was a trend for the second year. Again, barriers included transportation, distance from preferred church, no staff support to attend preferred services, and a preference to worship in a community church rather than through ministerial visitation to the home. Four people living in care homes related the problem specifically to lack of transportation. While the numbers are small, these results again raise questions about budget impacts on transportation and community activities. Like other cultural sensitivities, there is varying valuing of spiritual activities among providers, and varying accessibility within faith organizations. Visitors also noted some homes where individualized support was provided effectively so that consumers could participate in their preferred faith communities.

Summary Results by Category

Choice
The "Choice" category includes information about the ways that individuals identify their needs, wants, likes and dislikes; how they make major life decisions; how they make everyday decisions; the role they have in selecting providers of services and supports; and how their services and supports change as wants, needs and preferences change.

The majority of individuals visited were still satisfied with their choices. As previously noted, visitors did find an increase in individual dissatisfaction with the choices offered in care homes and day programs. Communication continues to be a barrier to making choices. Support staff often relied on ability to interpret the individual's personal communication relationally and without assistive tools, and often did not express concern about the dependency that engenders. Eleven individuals had restricted access to assistive communication devices, because they were unavailable in some environments, needed repairs, or direct care staff was not trained in their use.

Most people living in their own homes expressed satisfaction with the choices that they made in their lives Problems with limited choices were typically related to food and activity options. Other concerns related to room decorations, roommate selection, and service providers. Ten people, who were otherwise unrestricted in their right to make decisions for themselves, stated that they didn't agree with decisions that are made for them by family, staff, and in one instance, the Service Coordinator. An additional thirteen people did not agree with decisions made for them by family or significant others. The range of choice options continued to vary among service providers.

Relationships
The Relationships category includes information about individuals' friends and caring relationships; and whether they have community supports that can include their family, friends, service providers, other professionals, and other community members. Relationships are always central to the quality of an individual's life, and are frequently areas of concern.

Overall, 11% of the people visited identified relationship concerns. Sixteen people complained about problems with roommates, including fear of assault and frequent sleep

disturbance. One person expressed fears about a classmate at day program. The desire to find or spend more time with family continued to be the most commonly expressed issue. Twenty-one people wanted to visit out-of-area family and friends. Three individuals asked for help locating adult children. Both Service Coordinators and care home staff had usually tried to improve family connections. Alternatives like e-mail, video or picture exchanges were not often mentioned as strategies to connect families. Twenty individuals expressed loneliness and a desire for friendships. Two people wanted their partners to stay overnight at their care homes. Other concerns included using the phone and personal barriers to relationship.

Violence between partners was viewed as domestic violence, while violence between housemates or classmates was still viewed as a behavioral issue rather than an abuse issue. Again, visitors observed that there did not appear to be much concern regarding emotional well being and traumatic stress when assaults involved housemates who both used services.

Lifestyle
Lifestyle is a broad category, including if the individual is part of the mainstream of the community; if their lifestyle reflects cultural preferences; if they are independent and productive; if they have stable living arrangements; if they are comfortable where they live, and if children who are regional center clients live at home with their families. In part because of the range of the lifestyle category, the greatest number of concerns was identified under this category. Consequently, in the summation bar graphs, lifestyle concerns are broken down into three subcategories. As in previous years, issues ranged from small changes to lifestyle reordering.

As discussed previously, visitors found an increase in those who expressed dissatisfaction with day program services, from 9% in the previous year to 20% in this year. The foremost issue was the desire for paid employment, or better paid employment. Other issues included more time in the community and more activity overall. Twelve people wanted to take classes at community college or vocational school. Eight people wanted specific skills training, such a learning to crochet or learning to tell time. Nine people had transportation barriers that prevented them from being involved in their communities. One of those people was at risk of losing their job. One person wanted to learn to use public transportation. Three had lost their monthly bus pass, so that their dilemmas were time limited.

Cultural needs were identified in visits with 21 individuals. A familiar pattern, visitors observed that providers were generally making efforts to build cultural elements into the services they offered through menu offerings, activities, and home decor. American Anglo continues to be the dominant culture, which presented barriers to two Spanish-speaking parents whose children were living in foster homes. No community care facility visited used Spanish as the common language within the home. Cultural needs were also expressed for individuals of Hmong, Laotian, Samoan, and Chinese descent.

Six percent of adults and youth expressed the desire for more activities in the community, particularly on evenings and weekends. Specific requests included bowling, going to the mall, and garage sales. One individual identified access barriers related to wheelchairs and ramps. One parent identified needs for family recreational resources. Four people said that personal finances limited their social and recreational activities. Ten people mentioned that

their social/recreational services had been cut back at their care homes.

With the exception of 11 individuals visited, people were settled in stable housing. The problems were familiar. Finances, substandard housing, and relationship upheavals were the usual culprits. One had concerns about being forced to move after they transitioned to adult services, and one adult was fearful of having to move because of reduction in support services. In each instance, VMRC was well aware of the needs and working with the individual to resolve the problem.

The majority of people visited were in clean, safe, and reasonably comfortable settings. In addition to the 5% who specifically requested a change in residential services, 10% had issues regarding the comfort of their homes. Problems were typical of low-income housing. Household repairs, crowding, and drug-related activities in the neighborhood were among the most common problems. Two people had accessibility problems. Some of the problems identified in residential care facilities, were readily solved, such as moving the location of a TV set. Others were more problematic, involving relationships or overall dissatisfaction with the setting. Visitors noted a lack of cleanliness in two homes.

Visitors were again impressed by the thoughtfulness and care provided to children with complex support needs. They were also impressed by the affection they usually saw between foster parents and children. Three parents who had children placed in foster homes identified needs for support when the children visited their familial homes. These needs included training in care needs and adaptive equipment.

Health and Well-being
Visitors found that safety issues were carefully addressed for most individuals. Issues and the number of people expressing concerns have been similar in aggregate data annually. Individuals living independently or with supported living services almost always knew about 911 and how to get assistance in an emergency. Fifteen people did not feel safe in their neighborhoods. Three of those people had experienced assault or robbery. Each of these three was being assisted in locating different housing. Staff were able to specify how they would recognize that an individual who does not use words was ill or hurt. Five people were fearful of assault from other people who use services. Two people were waiting for equipment required for personal safety, and two people had safety needs that their planning teams were expecting to discuss at upcoming meetings. There was confusion regarding the status of a "do not resuscitate" medical order for one individual.

Ninety-seven individuals identified one or multiple wellness or health concerns. Twelve people asked for help in improving their health through exercise, diet, and smoking cessation. One person asked for help treating an addiction. For the most part, the remaining health needs were recognized by planning teams. Two people were waiting for appointments with specialists, one person was recovering from orthopedic surgery, and one person was waiting for surgery. Most support staff reported that repairs have been easier to secure in recent years. Eight people reported problems with medications, including nausea, vomiting, excessive sleepiness, and dizziness. Two family members said they were concerned for their family members' medications and asked if they could be included in upcoming planning meetings. In seven instances, day program staff expressed concerns about care home

attention to health needs.   These concerns included personal care, diet, and injuries.

Three people had health problems acerbated by situational problems, such housemate smoking or household mold.   Nine people described chronic sleep disturbance over a prolonged time period. Two people had infections or minor injury that had not been medically evaluated at the time of the visit.

Two individuals were having trouble accessing services because of disagreement whether their needs should be addressed by mental health services or other medical services. In one instance, the individual was at risk of losing the home placement as well.   Support people expressed frustration at the difficulty resolving service needs when mental health symptoms are too disruptive to be served in the existing community setting.   One child was receiving psychiatric services only after intensive intervention by the Service Coordinator, a significant success in the care for that child.

Sixteen individuals had needs regarding protecting their own health and safety.   Most commonly, people wanted to understand why they were taking the medications that they were taking, learn about 9-1-1, and learn how to respond to fire or earthquake.

Sixty-nine people identified a need for medical services that they did not currently receive, across all counties.   Eighteen people had health problems or risked injury because of problems with acquiring or repairing needed assistive equipment. Their planning teams were working to resolve their problems.   Twenty-four people had dental needs. Four women needed ob/gyn services, eleven people needed an optometrist, and four other individuals had needs for specialists such as physical therapists.   Access to mental health services was a problem for 6 individuals. Two people were waiting for health coverage through spouse or personal employers.   One person expressed the need for an AA group designed for persons who use regional center services. One person needed transportation for medical treatment outside the home community.

Rights
The Rights area of the LQA gathered information on the individual's exercise of personal rights as a person who uses services and as a citizen; whether or not the individual is free from abuse, neglect and exploitation; if the individual is treated with dignity and respect; if the individual is receiving appropriate generic services and supports; and if the individual has advocates or access to advocacy services.

The understanding that individuals had regarding personal rights varied widely, and was not necessarily related to the degree of supports being provided to that individual.   As in previous years, most visitors observed respectful and even affection interactions between individuals and the people who support them.   Fifteen percent of the individuals visited identified concerns in exercising their rights and responsibilities. By far the majority of these needs related to the individual's desire to understand their rights and services better, and to assert themselves more effectively, rather than to any restriction of personal rights. Visitor also found that while some people could indicate rights posters, they did not make the connection to ways that they could use those rights for themselves. Seven people wanted to attend the Statewide Self Advocacy Conference and/or self advocacy groups.   Thirteen

people had specific ways that they wanted to have greater control in their lives, related to spending money, activities, and cultural preferences.

Twelve individuals alleged violations of their rights that were potentially abusive or exploitive. Three of these complaints involved support staff, and one involved a guardian. Two people alleged physical and sexual abuse by housemates. The remainder of complaints involved family members.

Twenty-five individuals raised issues related to being treated with dignity and respect. Seven complaints involved teasing or harassment by peers. Eight individuals expressed feelings of disrespect from supports persons in their use of language, attitude towards privacy, and acknowledgement or honoring of personal preferences. Two complaints involved employers, and one a landlord. The remaining individuals had family difficulties.

Most people visited were using generic services and supports successfully, most typically public transportation, financial aid, and housing assistance. Twenty-six people identified problems. Most of these needs involved information about social security benefits, Section 8, transportation in rural communities, and accessing various social services. Five parents identified parenting support needs, including parenting skills training, and respite.

Fifty-two people expressed concerns related to advocacy services, including legal services. Fourteen people asked for help resolving various life problems or accessing services, including establishing credit, dial-a-ride eligibility, and working with Children Protective Services. Five people had specific legal needs related to divorce, Landlord/Tenant rights, and child custody. One individual requested assistance resolving a conflict with a conservator. Two family members expressed the desire to be more involved and have a better understanding of the individual planning process.

Thirty-seven people identified issues related to Service Coordinators and VMRC services. Some of the issues raised were matters of personal preferences, for example wanting a specific Service Coordinator. Five people had not met their Service Coordinators at the time of their LQA visits. Two people wanted to learn about the role of the Service Coordinator. Two parents expressed frustration in understanding the role and getting sufficient contact from their children's Service Coordinators. One parent identified transition planning concerns and did not think that VMRC would assist her. Fourteen people disagreed with decisions that their Service Coordinators made. The majority of complaints fell into three areas – frequent turnover of Service Coordinators, slow response, and unsatisfactory accounting information regarding personal funds. Individual account statements were requested again this year, by five individuals.

Satisfaction
The Satisfaction area of the LQA addresses whether or not individuals achieve personal goals; if individuals are satisfied with services and supports; and if individuals are satisfied with their lives.

Understandably, satisfaction is difficult to assess, particularly for people who do not use words to communicate. But for the most, people appeared to be content with their lives. People generally lived in attractive and comfortable settings, and felt that they were supported with care and respect. Almost half, 43%, of the people visited identified no follow-

up needs at all.   Of those who either shared concerns personally or had family or support staff share concern for them, most had already informed their Service Coordinators. There were many issues that impact life satisfaction, such as wanting more contact from family, that were most probably not resolvable through regional center services.

Hearing about people's dreams is an especially enjoyable part of LQA visits. Eighty-three shared future hopes. People wanted to get married, have children, own their own homes, and start their own business. Dreams also included traveling, writing a book, and increasing independence.

As already discussed, people talked about wanting different kinds of services, new day programs, different workers, and people who could help them achieve their ambitions. In addition to those issues already discussed in this report, 11 people expressed dissatisfaction with one or more support staff or service agencies. Twenty people visited expressed an overall unhappiness with life. While some of those individuals had specific problems that were overwhelming them at the time of their visits, most these individuals were characterized by persistent unhappiness over long periods of time.

Conclusion

As in previous years, the overwhelming conclusion of the data is that people are, for the most part, being supported in ways that meet their needs respectfully and effectively. The impact of low income is greatly ameliorated by support networks.

There are suggestions that budget constraints are having consequences to services and satisfaction. The number of issues raised related to health is now a three year trend, and may be related in part to the impacts of managed care. Difficulties accessing dental services are increasing. Problems getting second opinions, alternative health care, and wellness activities such as prostrate exams also raise questions both about access and provider bias. On the other end of the spectrum, visitors also found very complex medical needs being supported successfully. Some individuals also noted reductions in supported living services, weekend activities, and transportation in care homes.

The trend to increasing dissatisfaction with day program and care home services should be discussed in greater depth. It's important to consider the systemic barriers to programming, and whether or not there are changing expectations by consumers. As is true across the culture, people want more variety, more choices, and more economic freedom.